Building a Church for Strangers

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1. Stephen

Stephen is 17 years old and 5 feet tall. He has few words, and it is diffi-cult to tell precisely how much of the very limited vocabulary that he does have he actually understands. He is slightly overweight, and a little unsteady on his feet at times. His tongue protrudes a little, giving the impression that he is always smiling, which is not far from the truth, because much of the time he is. Stephen suffers from epilepsy, and has frequent and sometimes quite violent seizures, during which he sometimes sustains quite severe injuries. In view of this, for the past two years Stephen has worn a protective helmet for most of his waking hours. It is not the most beautiful of fashion accessories, but his carers have covered it in pictures of his favourite cartoon characters, and he seems to quite like that. As I watch that round smiling face, covered as it is with bumps and scars, I find myself moved with love, compassion and admiration. He is a strong boy who keeps on smiling in the face of circumstances that would defeat most of us.[1]

Stephen is diagnosed as having Down's syndrome with profound learning disabilities. His lack of linguistic ability and different cogni-tive functioning means that he is deemed to have very limited communicational skills and few self care skills. However, I'm not so sure about that. Certainly he is highly dependent on others to do the basic things in his life. He is also virtually unable to communicate through words. Yet anyone who has spent time with him knows that he is more than able to communicate at a number of other levels. Stephen's lack of verbal skills and his different cognitive functioning mean that his experience of the world is not determined by the boundaries of words and complex linguistic structures. He resides in a place where there are few words and where the power of reason and intellect cannot reign supreme. 'Stephen's world' is a place that he has come to know and understand through his emotions and feel-ings, hunches and intuition, signs and symbols. Stephen embraces and lives out those aspects of human experience that are often over-looked by a society and a church that frequently places reason, intellect and rationality above emotion, intuition and experience. Through the subtle gestures of love (gaze, touch, smile etc.) that most of us carry out without ever reflecting on their significance, Stephen

[1] For those with an interest in method, this monograph follows the shape of a standard practical theological reflective circle. It begins with experience, followed by social and theological reflection on that experience, before returning to the original situation with a revised form of ecclesial praxis.

reminds us of the holistic nature of human living and relating. In ways that are strange to us, Stephen uses his whole body; his entire being, to draw those around him into his inner world in a way that those of us who are limited by our dependence on one-dimensional logocentric forms of communication struggle to understand and reciprocate.

Although Stephen is diagnosed as having severe learning disabilities, in fact it is very difficult to assess just how much or how little ability to learn he actually has. Owing to his cognitive impairment and consequent inability to communicate through words, it is very difficult to discern whether Stephen is truly unable to learn, or whether his lack of learning is a result of the inability of those around him to function effectively within the communicative areas that form his life-world. If he has no access to information, he is unlikely to learn. Pippa Murray, speaking about her experiences with her own son, who was deemed to be learning disabled, puts this point well:

> I do not think that the terms 'profound' or 'severe' learning disability or difficulties (putting aside all issues of labelling) go anywhere near to an accurate description – from my own experience of my son. I have to admit that, in spite of us having a very close relationship and in spite of me wanting to think I knew more about him than anyone else, I have no idea what his 'learning difficulties' were, how much he understood or did not understand about both concrete and abstract issues. Perhaps, in spite of the outward appearance, he did not have 'learning difficulties'. I say this because I know children who have been labelled as having 'learning difficulties' and then have found a method of communication that they can use with the world. It has then become clear that there were no learning difficulties as had previously been thought or that the learning difficulties were different.[2]

Who knows, it may be that if we could find the correct 'communicational key', an appropriate non-verbal language, we would discover that Stephen's ability to learn is very different from the assumptions engendered by his diagnostic classification. It is interesting to reflect on the possibility that it may be those of us around Stephen who have learning difficulties, in that our cultural, economic, rational and medical assumptions and priorities prevent us from prioritising the development of the forms of communicational skills that would enable us truly to begin to understand and learn the holistic communication that is natural to Stephen.

[2] Pippa Murray, personal communication.

The mystery of worship

Stephen loves to worship God. He regularly attends the small hospital chapel, situated in a draughty portacabin a few hundred yards from the hospital ward that has been his home for most of his life. He has no idea about the theological technicalities of what is going on within the service of worship. He doesn't know the words of the liturgy, and he finds little meaning in the words of the prayers and the hymns. He simply knows it is a place where he can go to sing and be with his friends. He knows the word 'Jeeshuss", and takes great pleasure in shouting it out, often during the quietest part of the service. However, this 'disruption' is not a problem. Within the small hospital fellowship that is his spiritual home, there is a sense of acceptance and community that I have rarely experienced elsewhere; a feeling that we are 'church' in a very real and meaningful sense. Within the confines of that tiny sanctuary there is 'neither Jew nor Greek, slave nor free, male nor female... black nor white, able bodied and handicapped,'[3] only friends dancing and singing with 'Jeeshuss' their friend.

Yet still, I often catch myself wondering what is going on in Stephen's mind as we sing, as we speak, as we worship together. The services of worship he attends and enthusiastically participates in are obviously meaningful for him; the drips of well-earned sweat that ooze out from behind the slats of his hat and stream down his face bear ample witness to that. But precisely what that meaning is I will never know. As I watch him sing along with the hymns, embrace his friends, laugh with his carers, I find myself challenged at the roots of my faith. Something is happening in the life of this young man, God is moving in him, and I have no idea how to explain it. 'Jeeshuss' is with him, but not in the words of scripture that are spoken, or the complexities of the liturgy that is being worked through. These things mean nothing to him. God is with him in a way that transcends my intellectualised worldview, and makes me ashamed of the deep questions I ask of the theological implications of his situation. God is with him in the bread and in the wine, but not in any way that I have experienced or that all of my arduous theological training can explain or legitimise. In fact, my hopeless dependence on my intellect for making sense of the world actually prevents me from even beginning to understand how God might be with him in any kind of meaningful sense. The truth is that God is more mysterious and unpredictable than I am comfortable with imagining.

[3] F. Young, Face to Face: *A Narrative Essay in the Theology of Suffering.* T. & T. Clark, 1990, p. 192.

Stephen loves to sing

Despite his lack of words, Stephen loves music and he loves to sing. His favourite tune is the old Stevie Wonder song 'I just called to say I love you'. A strangely appropriate, if unconsciously rendered, sentiment that perhaps says more about the richness and simplicity of God's incarnated love than many long and complicated sermons. The words are almost incomprehensible, but the tune is unmistakable. He spends hours repeating that same line over and over again. I don't think that he has any idea what the words mean (although it is clearly impossible to tell), but his pleasure in the music is obvious.

The beauty of openness

Stephen is one of the friendliest and most straightforward people I have ever met. He is one of the few people I know with whom I am always sure that I know where I stand. Each time we meet, he greets me with a smile and a hug that reveals an openness that I would dearly love to emulate in my own life. Why I cannot achieve such openness in my life reveals to me how shallow my pronouncements about representing a New Kingdom of love, forgiveness and acceptance really are. His openness opens my soul to new possibilities of community and fresh, uninhibited ways of relating. His presence brings me peace and fresh revelation. But the revelation that he offers to me is embodied in such a way that it transcends and transforms my intellectual knowledge of God. Brett Webb-Mitchell tells the story of Sue, a young woman with learning disabilities, who is an active participant in her local church. He tells how during the first half of the service the atmosphere is calm, stiff and formal. However, when it comes to the passing of the peace, a remarkable transformation occurs.

> With the congregants standing, the priest says 'The place of the Lord be always with you,' and the people respond. 'And also with you.' At that point, Sue does something simple yet amazing: she turns around in her spot and not only passes but *becomes* the peace of Christ. Amid a rumble of moving feet and chairs, Sue's voice rises above the muffled ones nearby as she says, 'How are you, darling? It's so good to see you this day, lovie.' She hugs every person within her reach, whether she knows them or not, and then, slowly, the rest of the congregation starts to unwind, loosen up, and greet one another with an embrace or a warm handshake. In this church worship has become celebration.[4]

[4]   B. Webb-Mitchell, *Dancing with Disabilities: Opening the Church to all God's Children*. United Church Press 1996, p. 5.

When I read that story I realised that for me Stephen had become the peace; a living symbol of something which I deeply desired to have and to be; an element that was missing not only from my own spiritual life, but from the spiritual lives of many churches. I always assumed that it was he and others like him who were 'the least of them' that Jesus spoke to me about and told me to care for. Suddenly, in the face of his openness and trust, I realise that it is me who is the weak and vulnerable one, afraid to show my emotions, afraid to reveal the strength of my love for others for fear that it be perceived as weakness. When I am in Stephen's arms, I can taste the coming kingdom, and begin to understand what it might be like to live in a society where the emotional barriers that fuel my embarrassment at his meaningful caress are torn down by the power of unspoken, unashamedly revealed love.

An angel and a vagabond

However, lest I be accused of patronising Stephen, I would want to add that he is no saint. He is *not* one of the 'silent, suffering souls', created 'in innocence' and somehow occupying a space that is 'beyond the fall', in the way that some would portray people with learning disabilities. Certainly, as a human being made in the image of God, Stephen *is* one of God's chosen ones; in that sense, I believe that all human beings are. But Stephen has an edge that takes him beyond the image of helplessness and saintliness, and transcends the unhelpful pity that we are all tempted to yield to when in his presence. Whilst his openness and friendliness inspire me, Stephen is no angel. He is a real boy with that normal paradoxical mixture of angel and vagabond. He is incredibly mischievous, and will frequently pick the pockets of his carers and hide the contents in places where, to put it politely, one might not immediately think of looking. He is also becoming quite sexually aware which is posing difficulties for some of his carers. At the moment they are trying hard to develop ways of teaching him what is appropriate and inappropriate touch, without at the same time depriving him of a vital source of communication and mode of relating.

Although Stephen is generally a happy person, there are times when he is very quiet and obviously quite sad. Sometimes this is in response to something that has happened, but often it just seems to come upon him for no apparent reason. He will sit on his own for long periods of time either staring out of the window or staring at his hands. The look on his face tells a sad story, but it is a story that has to be inferred, because it cannot be told. It's strange, I feel that I know so many things that make Stephen happy, but I don't really know what brings on this sadness. His world is a clutter of emotions and feelings, some of which

he can express without any difficulties, but others are deeply personal, and destined to remain personal as long as we fail to develop the ability to communicate with him. All of us around him in some ways share his sadness as well as a sense of mutual frustration that we cannot get to the heart of his pain. We'd al love to take it from him, but, in a way that is really quite disturbing, Stephen has to handle his inner pain alone. All of our clever counselling and therapeutic skills are silenced in the face of his wordless despair. We can sit with him, we can be there for him, but we cannot truly share in his sadness.

As I watch Stephen in these times of deep sadness, I understand the truth of Elaine Scarry's observations on the nature and power of pain. Pain narrows an individual's horizons to the level of one aspect of their experience, thus closing them off from the richness and fullness of human existence. Pain either expands to fill the whole of our universe or contracts our universe and confines it within the boundaries of our immediate experience. The inexpressibility of pain

> comes unsharably into our midst as at once that which cannot be denied and that which cannot be confirmed ... whatever pain achieves it achieves in part through unsharability, and it ensures this unsharability through resistance to language. [5]

As Stanley Hauerwas puts it, pain 'is the enemy of community precisely because we cannot feel one another's pain.'[6] If this is so for those who have words, it is perhaps more so for those who have no possibility of expressing their pain verbally. Stephen's pain destroys the wholeness that is so fundamental to the way in which he encounters the world, and forces him inwards upon himself. His pain lifts him out of community and places him in an isolated place where I can barely reach him. The unsharability of his experience distresses me, and serves to alienate him from the very community that he is so inspirational in creating. His sadness is tragic, but my inability to reach him is equally as devastating.

Dangerous language

Stephen also has a pretty sharp temper, and he can, on the odd occasion, become quite aggressive and violent. However, I use the words 'aggressive' and 'violent' with some caution. To use these words is in a sense misleading and highlights the inadequacy of our structures of language to capture the nuances of Stephen's experience. Words are never value free or morally neutral. Rather, the meanings they take on

[5] E. Scarry, *The Body in Pain: The Making and Unmaking of the World*. Oxford University Press 1985, p. 4.

[6] S. Hauerwas, *Naming the Silences*. T. & T. Clark 1993, p. 146.

reflect the particular culture within which they are used and the power structures, social norms and commonly held assumptions upon which that culture is based. Words create worlds and profoundly affect those who inhabit these worlds and the ways in which these worlds are inhabited. Consequently, it is important to approach words such as 'aggressive' and 'violent' with a deal of discernment. Both contain certain assumptions that, I suspect, are not a part of the meaning of Stephen's actions. He does not have the moral capacity to think through the implications of his actions and he most probably does not have the intent to wound and maim in the way that the attribution of these words to his behaviour would imply. Although his actions may be interpreted as violent and aggressive acts, in fact, for the most part, they are not, at least not in the way that we normally use these words. Rather than being attempts to inflict pain or revenge on another person, most of the time his 'violent and aggressive actions' are communicative gestures designed to inform those around him of his inner pain, his confusion or his desire for a particular object. Also, although this may seem rather strange, sometimes they are in fact gestures of affection. When Stephen was younger he was everyone's favourite. His playful taps and cheeky antics made him the centre of attention and the focus of everyone's affections. Nothing much has changed in Stephen's behaviour since he was younger. However, he·is much bigger and stronger now and people tend not to find him quite so cute, and his 'playful slaps' are no longer funny either to the staff or to his fellow residents in the hospital where he lives. Stephen finds this difficult to understand. As far as he is concerned he is behaving in the same way as he always did, but the reaction from others is profoundly different. Understood within this frame it becomes obvious how frustrating and confusing this must be for him. What may begin as an affectionate game can very easily shift into something else as he struggles to make sense of his rejection and the negativity of people's response to his actions. In using the words 'violence' and 'aggression' to describe Stephen's behaviour, we run the risk of pathologising what are essentially communicational difficulties being experienced by carer and cared for.

It is vitally important to recognise that it is not possible fully to understand or to make any kind of judgement about Stephen or his behaviour unless one is prepared to take the time to get to know him and to try to understand the complexities of his life-experience. One of Stephen's main problems is not his cognitive deficits or 'behavioural difficulties', but rather the inability of those around him to understand his life experiences and to treat him with the respect and dignity that his status as a human being demands. Unfortunately many people fail to grasp this vital point. Often when out walking with him, people will recoil in horror as he approaches. They will cross the road when he

prepared to 'take the risk' of placing Stephen with its children. We left. The joy of worshipful encounter and the freedom to express his experience of God in his own terms, a freedom that was so important for Stephen within the safety of the hospital chapel, was no longer available to him, at least within that congregation. [9]

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[9] This type of exclusion is not uncommon within churches. Webb-Mitchell observes that:

Too often, worship is a place and a process where the segregation of people with disabilities such as mental retardation is practised. Liturgy, the prescribed use of certain rituals of communal worship in religious communities such as churches and synagogues, has often pulled family members apart rather than brought them together. Not only are children excluded from worship, but so are people with mental retardation, because they are perceived as being unable to understand and enjoy the intellectual breadth of the liturgy, especially the singing of hymns, the reading of scripture, the preaching, and the recitation of creeds and prayers in unison.

2. Whose problem is it anyway?

So what is it about Stephen's mode of existence that so disturbs both church and society? What is his problem? On the face of it one might be justified in assuming that the answer to this question is obvious. Stephen is learning disabled – he has a disorder that has resulted in 'a state of arrested or incomplete development of mind that includes significant impairment of intelligence and social functioning'.[10] His condition cannot be reversed or cured. A rough typology would suggest that, from a clinical perspective, learning disabilities fall into the following categories:[11]

Mild learning disability	A person has only basic reading and writing skills, but is fully independent in self-care. People with this level of disability do not encounter the health authorities, unless they develop specific difficulties that merit some form of intervention.
Moderate learning disability	A person is likely to have limited language skills, and might need some help with self-care. He or she may well be fully mobile and able to do simple practical work.
Severe learning disabilities	A person is able to use some words or gestures for basic needs, and will be able to undertake supervised activities.
Profound learning disability	A person will have very limited communication skills and no self-care skills.

Within this framework Stephen stands somewhere between the severe and profound category of learning disability.[12]

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[10] The Mental Health Foundation, *Learning Disabilities: The Fundamental Facts*. Mental Health Foundation 1993, p. 5.

[11] Adapted from Gerald Hales (ed.) *Beyond Disability: Towards an Enabling Society*. Sage 1996.

All of this appears to be a reasonably clear and apparently value-neutral structure, presenting an objective perspective on some of the technicalities of Stephen's condition. Such definitional structures may be useful for certain purposes. However, behind them lurks another dimension that is missed if our focus is bounded by the perspective of the medical model alone. Indeed, this type of categorisation runs the risk of presenting learning disabilities within a less than adequate explanatory framework; a framework that lays down universal principles and fails to represent the enormous diversity of life experiences which people with Stephen's impairments encounter. Such a way of categorising Stephen tends to engender and reinforce the types of destructive stereotypical assumptions highlighted previously. In short, we should not presume that Stephen can be defined and understood merely according to preconceived notions of how people within this category will behave and experience the world.

Of course, according to the particular clinical criteria used to define the various categories of learning disability – level of intellect, communicative ability, degree of independence – it is to some extent true that Stephen will appear to function at a limited level. However, such criteria are far from value-neutral, and, whilst telling us *some* things about certain aspects of Stephen's overall life experience, they perhaps tell us more about the type of society within which he lives. After all, the criteria used to categorise people do not arise out of a vacuum, nor are they objective or neutral. Rather they reflect and emerge from particular cultural milieu and contain the values, assumptions and priorities of cultures at specific moments in time. In other words, in another culture or at another time within the same culture, the particular categories that are used to define people with Stephen's impairments may be radically different. Forms of categorisation such as the typology presented above are deeply embedded within the medical model and the rationalism of post-Enlightenment Western culture. As Phil Smith puts it, people have described those with learning disabilities[13]

> with a variety of terms first as misfit or deviant, then idiot, imbecile, and feeble-minded, then retardate and moron, followed by mildly, moderately, severely, or profoundly retarded, and finally

[12] About 45,000 children and 63,000 adults diagnosed as having severe learning disabilities in the UK are cared for at home. Whilst at one time it could be assumed that 'the majority of people diagnosed as having severe to profound learning disabilities would be treated within a hospital context, with the current movement towards community care, the great majority of people who fall within this category live with their families or are cared for in community-based residential accommodation. The lives of people with severe learning disabilities now form a significant part of the fabric of our local communities.'

[13] Personal correspondence.

person with a developmental disability [learning disability in the UK]. These changes reflect movement towards an increasingly scientific and medically-based mapping of disability, and increased use of a numbered, taxonomic cartography of difference.[14] Such a cartography is based on the Western 'propensity for ordering complex variation as a gradual ascending scale'[15] and is a result of inherent 'metaphors of progress and gradualism.'[16] Giddens refers to these taxonomies simply as 'lists', and notes they have been used historically as tools of surveillance and control as each level of disability carries with it particular assumptions about the capabilities and life possibilities of those distinguished by the particular label.[17]

Why do we, therefore, within our Western culture, chose to create the category 'learning disabled'? Not all cultures, by any means, have a similar category, and it is not one that has always been present within our own. Why do we, in other words, single out the intellectual ability of people as particularly problematic? As we have seen, Stephen has gifts and qualities that, in terms of what is important to him, in many ways outweigh the particular intellectual deficits that he is perceived as having. At least, in terms of the manner in which he experiences the world, together with the hopes and expectations that he has for his life, it makes little difference to him whether his intellect is impaired. His life priorities revolve around a different set of criteria. Yet why don't we choose to prioritise and define him by his ability to love, his openness, or his need for friendship? The fact that, from a clinical perspective, we define him and his situation according to the perceived state of his intellect is a choice that highlights the priority reason and intellect have within our culture.

It is important to be clear at this point. I am not suggesting that we get rid of all forms of categorisation. There is a degree to which human communication depends on the categorisation of experience in order that we can make sense of it and act appropriately towards one another and the world. As rough indicators of certain common features, categorisation can be useful in enabling the development of appropriate methods of care, intervention and teaching strategies that will help individuals to live as fully as possible and make the most of their potential. However, all forms of categorisation and assessment have inherent dangers. Indeed, rather than simply being objective clinical criteria, they often reflect cultural expectations and can be 'used to

[14] See, for example, S. J. Gould, *The Mismeasure of Man*. W. W. Norton 1996.
[15] S. J. Gould, *The Mismeasure of Man*, p. 56.
[16] S. J. Gould, *The Mismeasure of Man*, p. 56.
[17] A. Giddens, 'Time-space distanciation', in P. Cassell (ed.) *The Giddens Reader*. Stanford University Press 1981/1993, pp. 185–190.

force individuals into categories that identify what is "normal" and to ostracise those who do not fit in'.[18] As Dawn DeVries correctly points out:

> it is precisely persons with disabilities who often suffer from this practice; they are identified, usually from birth, as abnormal people who will always need special help to overcome *their* handicaps.'[19]

When such categories are used in a reductionist way, i.e. when the category becomes the central way in which a person is defined and acted towards by society and the health professions, then definitions and categories can become agents of oppression, exclusion and de-humanisation.[20]

The medicalisation of disability

We live in an age that has been profoundly influenced by that period of Western history that has come to be known as the Enlightenment. Amongst the central ideas that have arisen from this period are such things as the *belief in progress* (where humanity is assumed to be master of its own fate and should approach the future with confidence in its ability to transform the world through the technological power of science and the effective use of reason), the assumption that *all problems are in principle solvable through the use of reason and technology*, and the belief that *people are emancipated, autonomous individuals*. Within such a cultural milieu, medicine and the medical model have come to provide the dominant discourse and epistemological framework within which we strive to develop our understandings, not only of what is healthy and what is unhealthy, but also of what forms of physical and psychological states and behaviours are accepted as normal.

The medical model assumes that a disorder has a specific aetiology, a predictable course, manifests describable signs and symptoms, and has a predictable outcome modifiable by certain technical manoeuvres.

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[18] D. DeVries 'Creation, handicappism, and the community of differing abilities', in R. Chopp and M. L. Taylor (eds) *Restructuring Christian Theology.* Fortress-Pres, 1994.

[19] D. DeVries 'Creation, handicappism, and the community of differing abilities', p. 129 (Italics added).

[20] Whilst acknowledging the significance and potential therapeutic benefits of categories, it is vital that we approach them critically and do not allow their limitations to shape our preconceptions of what *people* are as people rather than as categories. Whilst obviously having certain significant impairments, Stephen is affected but not defined by them. He is a person made in the image of God and loved by God above all other creatures, so it is vital that we place his humanity before any form of identifying label. I am certain that Jesus would call him Stephen, before he thought about anything else. As a follower of that same Jesus, I think that his example is worthy of emulation.

In this model, the illness or problem is understood as an isolated 'bad spot' which it is the task of the health professional to excise or control using whatever means are at her disposal. The objective is to return the individual to his previously healthy state and to enable him to re-take his former position within society. Within this model, health is defined primarily as the absence of disease or infirmity. Ill health is understood in terms of specific pathology that needs to be identified, categorised and eradicated. To be deemed healthy is to be freed from pathology and to experience life as closely to the expected social norm as possible.

Our thinking on issues of disability has become 'medicalized' in that the categories we apply to people with disabilities and the expectations that we have with regard to appropriate forms of care and rehabilitation are frequently based on the principles of the medical model. As Stanley Hauerwas puts it, it

> is almost impossible to resist descriptions that make being mentally handicapped 'a problem', since those descriptions are set by the power of the 'normal'.[21]

Disabilities of all types tend to be construed as essentially pathological states which are in need of treatment or manipulation in order that people can be shaped into as close an approximation of what is considered normal as possible. Two stories will help us to get to grips with the medical model's power to define what is normal and how normality can be achieved.

Changing faces

This first story relates to a recent Channel 4 television programme: 'Changing Faces'. This documentary traced the story of three people with Down's syndrome, two children and an adult man, who, in a quest to attain 'normality', had embarked upon extensive surgery to remove the syndrome's features. In very graphic detail viewers were taken through the process whereby the faces of these three people were altered by surgery, in an attempt to remove the features of Down's syndrome. The pain and discomfort that the children went through was, to say the least, distressing. However, perhaps more distressing was the rationale given by the adult man, Peter, for having his face-altering surgery. When asked why he wanted to change his facial features, he replied: 'so that I can get a friend'. The loneliness, isolation and deep stimatisation felt by people with learning disabilities was rammed home by Peter's sadness and the tragedy of the hope he had invested in medicine to mend his broken places. The idea that the difficulties encountered by these three people could be eased by

[21] S. Hauerwas, *Dispatches from the Front.* Duke University Press 1995.

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the use of medical intervention focused on eradicating specific 'problems' within the individual poignantly reveals the power of the medical model in shaping our responses to difference.

The healing hand of God?

The second story comes from within the church community. One might assume that a church that proclaims a radical gospel of love and acceptance, based on the profoundly humanising ministry of Christ, would offer a vital corrective to the negative attitudes, values and understanding that are so prevalent within society. Unfortunately this is not always the case. I recently attended an evangelical meeting that had as its central focus the reality of divine healing. The speaker told the story of a child who had Down's syndrome. He told how her parents took the child, Lucy, to a healing service and there before the eyes of the congregation, the child's features changed and she became, quote: 'normal'. Now the speaker thought this was tremendous. I found it deeply disturbing. It seemed to me that what we were witnessing here was a theological extension of the medical model without any critical reflection on the implications of what was being said. What was this story saying about the value and worth of people with learning disabilities, when God appears to want to transform them into something other than the unique individuals they are? What was the 'healer' rejoicing in? Did he think that the fact that Lucy had been 'healed of Down's syndrome' meant that she had moved closer to the image of God than she had been previously? Who was this new girl? Who was this revised person, stripped of her history, stripped of her past, reborn at six years old? In what way did the injection of reason and intelligence and her revised facial features change her for the better? Did she discard her past 'disabled life', and simply carry on as if she had never had Down's syndrome? If that is so, what does it say about the worth of the lives of others with Down's syndrome, that God can so easily discard their history? Whether or not one accepts the story as 'truth', it nonetheless contains a theological rationale for the problematization of disabilities and a form of intervention, in this case divine intervention, that fits neatly within the general approach of the medical model.

The social construction of learning disability

All of this brings us back to the question of precisely what Stephen's problem is. It is of course true that he has impairments and serious difficulties. These need to be taken seriously and effective forms of intervention and help must be developed. Nevertheless, Stephen's problems are not simply confined to his epilepsy or his intellectual and

cognitive impairments. Significant as Stephen's particular, personal impairments undoubtedly are, his disability comprises considerably more than malformed or damaged biology, or an inability to achieve a culturally defined level of intelligence and learning. As has been suggested, many of the difficulties he experiences have to do with the type of society he inhabits and the sort of value systems, priorities and images of fruitful human existence that are assumed to be normal.

Those whose thinking has been shaped by the principles of the medical model tend to assume that Stephen's problems are located within and specific to Stephen. His condition is viewed as a 'personal tragedy'[22] and his difficulties are looked upon as a *challenge* to be dealt with or an *obstacle* to be overcome. From this perspective the emphasis in terms of care is on dealing with Stephen and his discrete personal problems. This understanding necessarily prescribes particular solutions, treatments or therapies, in this case not to cure Stephen but to correct his behavioural, relational and social functioning. Thus, correction or psychological manipulations aimed at enabling him to function within established social structures tend to be viewed as the primary means by which he can achieve acceptance and be successfully assimilated into society. If he fails to become appropriately socialised or corrected he will find himself marginalised and relegated to the social status of 'invalidism'. Now, the important thing to draw from the term 'invalid' is that it marks a person out as existing in a form which is *invalid*, in that it is not socially accepted as a valid form of human existence. Under such circumstances, society does not assume any necessary responsibility for Stephen's disabled condition and consequently has no need to change in response. Stephen is severely learning disabled, therefore it is assumed that he has to be cared for by professionals or specialists with specific qualifications and experience whose task it is to enable him to develop the necessary skills to function as closely to the expected norm as possible. [23]

From the perspective of the church, such an understanding manifests itself in the assumption that its primary task in caring for Stephen is to find ways of enabling him to develop the necessary skills to be able to function, in a non-disruptive manner, within the structures of worship and fellowship as they stand at the moment. The task of the church is not to change or re-think its theology or practice in response to Stephen's needs, but simply to discover ways in which he can be made to fit within the church structures as they are at the moment. The problem is *his*, and the church seeks ways to respond to the immediate particularities of *his* difficulties. Indeed, if we reflect on Stephen's brief

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[22] M. Oliver, *Understanding Disability: From Theory to Practice.* Macmillan 1996, p. 31.

[23] This section is adapted from a paper originally presented to the John Macmurray conference held at the University of Aberdeen in 1998. The title of the paper was 'Constructing Persons: The Philosophy of John Macmurray and the Social Construction of Disability'.

encounter with his local church, it is obvious that he was perceived by the representatives of that church community as someone with a specific problem that had to be dealt with or solved. The church felt under no obligation to commit itself to Stephen, or to change in response to his needs. Rather in the name of orthodoxy, 'right worship' and fairness to other worshippers, the church felt justified in excluding Stephen from the worshipping community.

The problem with approaches that focus solely on the individual and his impairment, is that they ignore the crucial fact that Stephen's disability is not confined to his chromosomal deficit or his epilepsy, but has a wider social dimension which is fundamental to his life experience. In order to understand this dimension, it will be helpful to begin by drawing out the distinction between 'impairment' and 'disability'. By impairment I mean the discrete functional limitations that are present within individuals, which cause some manifestation of physical, mental or sensory impedance. Disability, on the other hand, relates to the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and/or social barriers. Thus whilst people diagnosed as having severe learning difficulties may be seriously impaired by genetic difference or neurological damage, they are not necessarily disabled by them. Dependency, vulnerability, limited intellectual capacities and the lack of ability to learn do not necessarily lead to the type of stigmatisation, marginalisation and limiting of social opportunities that are a significant feature of Stephen's disablement. Rather it is society that, by placing barriers and developing systems of valuing and social expectations which exclude, stigmatise or downgrade particular groups of people, transforms Stephen's impairments into disabilities. '

> Within a society which uses the criteria of *independence, productivity, intellectual prowess* and *social position* to judge the value of human beings, people with intellectual disabilities will inevitably be excluded and downgraded as human beings of lesser worth and value.[23]

If society were structured differently and had an alternative system of values and expectations that was not dependent on these criteria for valuing and categorising people, the concept of learning disability would not exist. Within a society that refused to pathologise difference or worship intellectual prowess and which adhered to different values, ways of relating, and social and moral priorities, people would simply

[23] J. Swinton, 'Learning disabilities: who's problem?', in *Scottish Journal of Healthcare Chaplaincy*. (1) 1, 13. See, also, S. Hauerwas, *Suffering Presence: Theological Reflections on Medicine, the Mentally Handicapped and the Church*. T. & T. Clark 1988, pp. 159ff.

accept the differences of the other and seek to find ways of effectively living together.

A story will help to clarify what is being said here. Stanley Hauerwas tells of a woman with Down's syndrome who attended the same church he did when he was younger. Dorothy used to help the teacher in Sunday school by handing out pencils, checking names in the roll book and collecting the pencils at the end of the session. Hauerwas and the rest of the children merely assumed that she was the teacher's assistant.

> It was much later, when we were nearly all grown up and adult, that the world told us that Dorothy had Down's syndrome. At the church we were under the impression that Dorothy was the teacher's assistant.[24]

These children had to learn that Dorothy was disabled. Within the particular culture of Hauerwas' church, Dorothy did not have learning disabilities or Down's syndrome. She was Dorothy, the teacher's assistant. It was not until she was named and categorised that Down's syndrome came into existence and Hauerwas recognised the 'strangeness' of their encounter.

These are important observations for the church in its pastoral care of Stephen. If we seek to develop pastoral strategies that focus purely on how best to cope with his cognitive limitations or his epilepsy, we will fail in our efforts truly to care for him in a way that is transformative both for him and for the wider society. If the difficulties encountered by Stephen are at least partly caused by society, and by implication by the Christian community itself as part of society, then none of us can abrogate responsibility for changing disabling attitudes and values that exacerbate the difficulties he encounters. Each one of us, to a greater or lesser extent, is responsible for disabling and invalidating Stephen. By implication, each one of us is equally responsible for enabling him and revalidating his life. If we are effectively to respond to Stephen, what is required is a form of community and a system of valuing human beings that will enable him and others like him to find a respected, valid and valued place. It is in pointing towards the development of such a community that the remainder of this monograph will find its dynamic and goal.

[24] S. Hauerwas, *Resident Aliens*. Abingdon Press 1989, p. 93.

3. Beyond normalisation: creating an inclusive community

The fundamental problem

Reflecting on Stephen's life in the ways that we have been doing, it becomes clear that the fundamental problem is that many people do not understand the fundamental problem. Whilst most of us assume that his 'problem' is that he has Down's syndrome, in reality his problems reach beyond the boundaries of his own body and into the social milieu within which he lives out his life. An effective pastoral response must seek to avoid reductionist assumptions, and take cognisance of the fullness of Stephen's experience as the church strives to offer him meaningful care. Such a response will demand much more than simply attempts to 'normalise' Stephen within the structures of the church as it stands. A focus on 'normality' can be tyrannical and can lead to exclusion on a number of levels. In order truly to include Stephen, both physically within our communities and psychologically within our worldviews, it will be necessary to reflect on ways in which we can develop alternative forms of community that can accept his difference without pathologising it. Communities that can offer a loving context for the necessary revalidation of a life that is frequently invalidated by stigmatising attitudes and ill-informed prejudices. For current purposes I want to focus on how the Christian community might respond with effective revised pastoral praxis, on three levels:

Theological response	How might we include Stephen's experiences and perspective on God within the continuing process of theological development?
Interpersonal response	What particular form of relational intervention might be appropriate to enable Stephen to find a valued place within our communities?
Liturgical response	What kind of pastoral response can the church as a worshipping community offer to Stephen?

In reality of course each one of these responses is inextricably linked to the others. However, for present purposes it will be helpful to examine them separately.[25]

Encountering love's vulnerability: theological responses from a pastoral community

Christ with Stephen

The gospels tell us that Christ is present with those who are oppressed, excluded and misunderstood.[26] As we have reflected on Stephen's life, it has become clear that exclusion and lack of understanding form a central part of his lived experience. In an age that worships reason, productivity, independence and competitiveness, Stephen ranks amongst the marginalised and the excluded, and as such is someone whom Christ is with in a special way. Jesus tells us very clearly that whatever we do to those considered the 'least' amongst us we do to him.[27] If we take this seriously, then in a strange way, encounter with Stephen is an encounter with Jesus. Such a suggestion has important implications for the ways in which we understand God. As Arthur McGill puts it:

> The challenge of learning to know, be with, and care for the retarded is nothing less than learning to know, be with, and love God. God's face is the face of the retarded; God's body is the body of the retarded; God's being is that of the retarded. For the God we Christians must learn to worship is not a God of self-sufficient power, a God who in self-possession needs no one; rather ours is a God who needs a people, who needs a Son. The Absoluteness of being or power is not a work of the God we have come to know through the cross.[28]

When we encounter Stephen we are faced with a deep revelation of the nature of God as we are reminded of the dependency, neediness and interconnectedness that is a mark of the very being of the Trinitarian God. Human beings made in God's image are interdependent creatures: dependent on God and dependent on one another. Whilst this

[25] There is of course a fourth and equally significant aspect that must be dealt with, and that has to do with the social and political issues and of disability. Limitations of space prevent me from developing a social response here, but the basic question that needs to be addressed is how the church as a force for social and political change should react to Stephen's situation.

[26] See, for example, Matthew 21:31; 25:34–45; Luke 7:34.

[27] Matthew 25:34–45.

[28] S. Hauerwas quoting A. McGill, *Suffering: A Test Case of Theological Method in Suffering Presence*, p. 178.

dependency may be more apparent in Stephen's life, his experience is no more than a concentrated reminder of the state of all human beings. In this sense Stephen is seen to be 'different' not because he bears the label 'profoundly learning disabled'. He is different in that he openly reflects aspects of God that tend to be de-prioritized by Western culture and theology: that part of God that is intensely desirous for and dependent on relationships, divine and human; those aspects of the mystery of God that words cannot express and which function in ways which transcend rational knowing.[29]

Stephen reminds us of the vulnerability of human beings and ultimately of the vulnerability of God. When I see people physically holding Stephen's arms to his side, in an attempt to prevent him from sharing his affection, I recognise the vulnerability of love and witness something of the pain and rejection of the cross. As soon as one loves or seeks to offer love to another, one opens oneself up to the possibility of suffering and rejection. Suffering and vulnerability are the inevitable consequence of God's passion for the world. In Christ God reveals the vulnerability of love, both on the cross and in his willingness to accept scorn and rejection by becoming friends with tax collectors and sinners. Likewise for Stephen, suffering and vulnerability are the inevitable consequences of revealing love and affection in a world that has forgotten how to love and how to reciprocate love given freely and openly.

The body of Christ as Stephen's body

If encounter with Stephen is in some sense encounter with Christ, this has significant implications for the shape and texture of the Christian community. If God is for the poor and the outcast, as the liberationists have suggested, then our image of the Body of Christ must be formed and shaped not by the strong and the powerful (those who lay down the criteria for cultural, theological and aesthetic norms), but by the outcast and the marginalised; by those whom the world assumes to have no voice and to be of little significance. Stephen cannot be understood as in any way standing apart from the community, marked and stigmatised by his difference. Quite the opposite, in Christ we stand together as one body,[30] called to share one another's burdens,[31] and to sacrifice ourselves for our friends.[32] The intimacy of the Body of Christ is made clear in St Paul's analogy of the body as representative of the interconnectedness of the Christian community. Within the Body of Christ 'those parts of the body that seem to be weaker are

[29] Romans 8:26.
[30] Romans 12:4–5.
[31] Galatians 6:2.
[32] John 15:13.

indispensable'. The worth of individuals is not dependent on achievement, intellect or any other human attribute. Worth is given to individuals as their uniqueness is acknowledged and their centrality to the health and shape of the body is recognised and worked out in the loving practices of the people of God.

For St Paul, the commitment, intimacy and interdependency of the community is so intense that 'if one part suffers, every part suffers with it'.[33] It is important that we think through the implications of what Paul is saying. If each part shares in the suffering of the other, then Stephen's condition is not a 'personal tragedy', but a shared experience. *He* doesn't simply have Down's syndrome, *the Body of Christ has Down's syndrome*. When Stephen is excluded, stigmatised and misunderstood, so also is the Body of Christ. When society fails to see the beauty of those who are different, it fails to recognise the nature of the beauty of Christ. When Stephen is excluded from worship in the name of 'peace', we cease to be the Body of Christ in any kind of meaningful sense. Instead Jesus finds himself sitting with Stephen outside the walls of the church as we continue to praise, oblivious of his absence.

What we find, as we reflect on, and allow ourselves to be challenged by an image of a God and a people who share fully in the experience of Down's syndrome, is a fresh revelation of who God is, where God sits within society and ultimately what it means to be the church. We find an image of God that challenges us to enter into commitment and solidarity with Stephen, not in an attempt to change him or insist that he conforms to a pre-set social or ecclesiological norm. Rather, we are called to offer loving relationships which image the relationships of Jesus and to share in his experiences as together we discover what it means to live our lives in the image of God.

Of course the Body of Christ does not have Down's syndrome, in the same way as it is not literally a body. We are stretching towards understanding through analogy and metaphor. However, by exploring the nature of God and the church in this way, it is possible to point towards the simple but crucial fact that Christ is with Stephen, that Stephen is an integral part of the Christian community and that he is created in the image of God as fully and as beautifully as anyone else.

No need for healing?

This being so, Stephen's condition does not require healing or medical intervention. Quite the opposite, Stephen healed would cease to be Stephen. As Francis Young puts it with regard to her own son who is learning disabled:

[33] Corinthians 12:26.

> There is no 'ideal Arthur' somehow trapped in his damaged phys-
> ical casing. He is a psychosomatic whole.... What sense would it
> make to hope for 'healing' in cases like this?... There are twenty-
> two years of learning process that he has missed out on. In what
> sense could we expect normality, even if the physical problems
> were sorted out?... Arthur has personality at his own limited
> level.... Healed he would be a different person.[34]

It is important to be clear on what is being said here. I am not
suggesting that God does not heal, or that healing of illness and
disease is somehow wrong. What I *am* saying is that learning disabil-
ities are not illnesses or diseases that need to be healed or cured. Such
an understanding is the product of thinking that assumes the
normalcy of the approach of the medical model. 'Learning disabilities'
are not things that need simply to be diagnosed, categorised,
controlled and excised. Rather, they are human experiences; ways of
existing in the world, that need to be understood and respected as
authentic forms of human existence which reveal something of the
image of God. There is therefore no need for Stephen's condition to be
healed in the 'miraculous' way that it was suggested Lucy was healed.
He is not ill. If by some miracle Stephen was to be stripped of his
Down's syndrome, he would no longer be Stephen. His condition
should not be conceptualised as illness or disease, but rather as differ-
ence, something that needs to be accepted, understood and loved
within the context of his life. Stephen's primary identity is a *person to be
loved*, not a problem to be solved. His importance to the shape and
texture of the Christian community is beyond measurement. Stephen
is a unique individual who contributes to and shapes the Body of
Christ, not as what he might have been, or what he could become, but
as he is at this moment in time.[35]

If any healing is required, it is a healing of our perceptions and
understandings and the destructive social atmosphere that forces
people to feel the need to change their faces in order to feel accepted.
Healing, in its true sense, can come when all of us come to realise

[34] F. Young, *Face to Face.* p. 22.

[35] In addition, it is a fallacy to think we could do away with such 'abnormality'. If we
managed to weed out of the population all people, say, with an IQ below a certain
level, all that would happen would be that 'normal' would move, and we would have
a new set of people designated as being 'below normal'. The idea of trying to make
everyone 'normal' through whatever means (faith, prayer, genetic manipulation, etc.),
as well as not making spiritual, ethical or aesthetic sense, doesn't make practical
sense. At base, it is sheer arrogance on the part of those of us with 'normal' intelli-
gence (or physical capacity, or any other capacity) to think that we are of more value
to God or wo/man than someone with less of that particular capacity. (I am grateful
to Dr Alice Keiger of the Centre for Advanced Studies in Nursing in the University of
Aberdeen for this invaluable insight.)

that Stephen's face reflects something of the face of Christ. As such he is ensured a place of honour and value within the kingdom of God and amongst the people who are called to image and reveal that same God.[36]

Building a church for strangers: interpersonal responses from a pastoral community

Stephen needs friends. He is tremendously vulnerable. His knowledge of the world is narrow and his experience of the church is 'pure', in the sense that he has never encountered formal liturgy and the types of conservative and frequently exclusionary attitudes that often accompany it. All of the social and interpersonal forces that have been highlighted thus far will come crashing in upon him the moment the hospital gates close at his back. As he moves out into the community he is going to require a tremendous amount of support and encouragement to enable him to widen his horizons and learn the ways of the world. Whilst his needs will be manifold, perhaps the greatest pastoral gift that the church community can offer to Stephen is the gift of friendship. Friendship encapsulates something of the mystery of the incarnation and points towards the one who moved the status of his followers from servants to friends; from its to thous. As such it is a particular form of human relationship that provides a radical counter to the types of depersonalising and disabling structures, values and attitudes that are so destructive to the life expectations of people with learning disabilities.

Importantly, in the light of the ways in which people with learning disabilities are invalidated, devalued and disrespected, friendship provides individuals with a sense of value and belonging and, as such, is a powerful source of revalidation. This point is worth developing a little further. David Pailin highlights the ways in which people with learning disabilities are profoundly devalued by the social expectations of Western culture. As we have observed, the Western emphasis on productivity, competitiveness, intellectual prowess and social success means that people with learning disabilities are excluded from

[36] This of course does not explain why people in Stephen's situation exist. However, it does suggest that theologically, in answering this question it might be more fruitful not to begin by exploring the origins of evil, original sin, fall and so forth. Such an approach inevitably juxtaposes sinfulness with disability, with all of the negative implications that such a connection has for disabled people. It is also highly reflective of an Enlightenment mindset that seeks to explain everything according to the laws of cause and effect. Perhaps, it might be more appropriate to begin by asking what we can learn from people with learning disabilities about the nature and purposes of God. If we shift our starting point to God's love and grace, rather than human fallenness and God's judgement, perhaps we can develop a different theological understanding of people with disabilities and their place within our communities.

vital sources of value and self-esteem. Pailin presents a relational model of value and valuing that is very different from the cultural norm. He highlights the often overlooked fact that the things that people value are not valuable in and of themselves, but rather, they become valuable according to what they mean to others. Thus, for example, a family portrait may be invaluable to the family concerned, but have tantamount to no value outside of that family. A friendship ring may be of inestimable value to a friend and of absolutely no value to a jeweller. The value of the picture or the ring stems from and depends upon the attitude of others towards it. Pailin suggests that a similar principle is appropriate for an understanding of how human beings gain their value.

> Worth is not something that belongs to a person as a solitary indi-vidual. It is given to each person by the way that others, including – and ultimately – God, regard him or her.... Self-esteem is the product of being of worth to others.[37]

The worth of a person lies in the love of others for that person. In other words, human beings become valuable and develop a sense of being valuable as they encounter one another in loving relationships. This does not of course mean that some people are more valuable than others according to the level of relationship they experience. Human relationships are but reflections of God's relationship with humanity. Although it is reflected in loving human encounters, humanity's ulti-mate value does not come from human experience. Each person is equally loved and equally valued by God. Human beings gain their ultimate value from the knowledge that they are loved, valued and eternally held by God.[38] The Christian community is called to reflect this divine love in its daily encounters with others. Friendship is one context for the manifestation of this reflected love as the Christian community seeks to image God in His embracing and caring for those deemed to be 'unlovable' by conventional society.

If, as Jean Vanier suggests and as has been suggested by the argu-ment of this monograph, the 'particular suffering of the person who is mentally handicapped, as of all marginal people, is a feeling of being excluded, worthless and unloved',[39] then the simple act of offering trusting friendships can enable people with learning disabilities 'to begin to discover that they have a value, that they are loved and so

[37] D. Pailin, *A Gentle Touch: From a Theology of Handicap to a Theology of Human Being*. SPCK 1992, p. 118.

[38] The process of bestowing value through relationship is something that is fundamental to what we are as human beings created in God's image, as we are called to reflect some-thing of this divine love in our personal encounters. Thus even the 'socially unloved' remain of ultimate worth and are held and sustained by the all-embracing love of God.

[39] J. Vanier, *Community and Growth*. DLT 1979, p. 3.

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loveable.'[40] In this way the gift of friendship offers a relational space for what Francis Young[41] calls a transvaluation: a movement towards a radically new system of valuing that is fundamental for the development of truly inclusive community.

Loving Stephen

The pastoral beauty of friendship for the Body of Christ is two-fold. Firstly, friendship is important because Stephen is used to having friends around him. He knows what friendship is because he has experienced friendship in community. Because friendships do not necessarily demand words, it is a relationship that is open and very much available even to those whose impairments are as severe as Stephen's. Friendship functions at the level of intuition and experience rather than cognition and intellectual understanding. It therefore provides a vital relational conduit through which the love of Christ can be poured.

In a very real sense Stephen associates church with friendship: it is a place where he goes to be with his friends and to sing songs about 'Jeeshuss'. It is a place where he finds acceptance, affirmation and a sense of belonging. It is this sense of coming together as friends of God and of one another that gives added poignancy to the service of worship within the hospital chapel. One of the beautiful things about worship within the boundaries of the hospital walls is that each person within the service considers the others to be friends, that is people whom he or she trusts, desires to relate to and enjoys spending time with. Even those whose behaviour is at times awkward or distracting are accepted and incorporated into the service of worship. There is a strong sense of solidarity and oneness and people often get very upset if professionals try to remove others who are deemed to be distracting.

It is this sense of solidarity with the 'unloved' that is frequently missing from the praxis of the contemporary church. Because we don't take seriously the type of community-oriented 'body theology' that has been presented above, the Christian community, sometimes consciously, sometimes unconsciously, adopts the types of exclusionary attitude and practice which serve to alienate and stigmatise people with disabilities of all types. The fundamental difference between Stephen's encounters within the hospital chapel and the local church is that in one context he was considered to be a friend, someone to be loved and cared for, whilst in the other he was considered to be a stranger, a problem to be dealt with. The task of the church in her pastoral ministry is not simply to find Stephen a *space* within our church communities. Effective pastoral care

[40] J. Vanier, *Community and Growth.* p. 3.
[41] F. Young, *Face to Face.* p. 144.

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means ensuring him a valued and valid *place* in our lives, which offers him respect, acceptance and revalidation, and seeks to connect with him not at a superficial level, but at the core of his being.

> 'To live with' is different from 'to do for.' It doesn't simply mean eating at the same table and sleeping under the same roof. It means that we create relationships of gratuity, truth and interdependence, that we listen to the handicapped people, that we recognize and marvel at their gifts.[42]

To offer pastoral care to Stephen is more than simply to do things for him. It means finding ways in which we can live with him and for him, through the development of relationships based on respect, solidarity and commitment. The task of the Christian community is to discover ways of building a church for 'strangers'. Friendship is one vital foundational block upon which such a task can be achieved.

A community of friends

Secondly, friendship is a relationship that is freely available within the Christian community. Each one of us, at least in potential, is capable of offering friendship to Stephen and all who share similar impairments. Friendship is a learned skill based, amongst other things, on social opportunity. One learns how to develop friendships as one encounters others in community. As one experiences friendship, so one is enabled to share that experience with others. One of the main difficulties for many within the church community is that they simply do not encounter, or are unaware of, many of those who are marginalised within society. Men and women who suffer from AIDS, people with mental health problems, those with severe learning disabilities, whilst often 'with us' in the sense that they are part of our communities, still frequently go unnoticed. Because of this, many people do not gain the opportunity of learning how to become friends with those whom they might perceive as in some way different.[43] Nevertheless, as social psychologist Nicky Hayes points out, whilst in terms of friendship formation and development people tend to be inclined towards those with whom they can most closely identify, they tend to befriend those with whom they have regular contact.[44] Even if they are quite different in many respects, there is a tendency to come to like people simply as a result of having regular personal contact with them. 'Natural' fear can be overcome and transformed in the act of encountering one another in

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[42] J. Vanier, *Community and Growth*. p. 106.
[43] J. Swinton, *From Bedlam to Shalom: Towards a Practical Theology of Human Nature, Interpersonal Relationships and Mental Health Care*. Peter Lang 1999, (in press).
[44] N. Hayes, *Principles of Social Psychology*. Lawrence Erlbaum 1993, p. 78.

friendship. The fear of encounter only ever disappears in the encounter itself:

> the less one knows about the lives of those with disabilities, the greater becomes the fear of them. It is this fear that is disabled through encounter and through communal life with persons with disabilities.[45]

The missionary task of the pastoral community will be to reach out and begin to break down unnecessary social barriers that prevent the Body of Christ from noticing and caring for 'the weak'. This will entail active strategies to liaise with families, groups and organisations who are working with people either living in or about to enter the community. It will mean committing ourselves to offer respite care for families who are struggling and sometimes broken by the pressures of caring for loved ones in their homes. It will mean opening the doors of our homes and our churches and inviting these 'strangers' to come in and transform our lives. It will be a painful and costly form of care. Befriending strangers was one brick on the road to the cross of Christ. When we commit ourselves to this form of friendship, we have to be in it for the long haul. Too often I have seen people embark upon 'ministries of befriending' only to see them get bored and move on after a short period of time with a devastating effect on those who have been befriended. Stephen needs friends who will be with him in solidarity, in the way that his friends have always been with him. To befriend strangers is to be like Christ. To be like Christ is to walk the way of commitment and sacrifice even unto death. But when we act in these ways, our personal lives will begin to take on the shape of Jesus and the Body of Christ will begin to be made whole.

Preaching without words: liturgical responses from a pastoral community

Encountering one another in worship

A foundational part of the church's life in community and friendship involves being together in worship. It is within the intimate communion of worship that we encounter and reflect upon the mystery of God and discover the deeper meanings of being together as the Body of Christ. It is here, when the Christian community gathers together to pray and to praise that the unifying, humanising power of God's love for *all* people is revealed and worked out in tangible and deeply meaningful ways. In worship, the community gathers together

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[45] J. Moltmann, 'Liberate yourselves by accepting one another', in N. L. Eisland and Don E. Saliers (eds), *Human Disability and the Service of God: Reassessing Religious Practice.* Abingdon 1998, p. 113.

and enables each member of God's people to express his or her love for God in ways that are palpable, experiential and intense. It is within the shared experience of worship that Paul's proposition that all are equal in Christ irrespective of their differences is embodied and acted out by the Christian community.

Those like myself who come from the reformed wing of the church will find this rather experiential understanding of worship a difficult idea to accept. In worship we still focus primarily on the Word of God as it is proclaimed and expounded through words. It is therefore difficult for us to grasp the sense of celebration and whole-bodied experience that is obvious in Stephen's approach to worship. The types of art, drama, dance and music that make the chapel service so vibrant are alien to our sense of the holy and the sanctity of worship.

But what is worship if it is not a celebration? In the liturgy we recall and reflect on the saving acts of God as they are recorded in scripture. We celebrate the presence of God in our daily lives and lay before Him our deepest fears, joys and hopes. As we worship together we search for and find the sense of the holy in our everyday experiences and together develop hope in the goodness of God, giving thanks for the richness of the possibilities of the future. The expression of such things requires much more than words alone. It requires that we engage with these experiences with the whole of our beings. It requires that we 'become like little children',[46] not in a way that infantalises us, but in the sense that, in worship, we learn what it means to be able to attend to an experience without naming it, to wonder without words,[47] to love God with our hearts as well as our heads. Attending to an experience without naming it is something that is quite alien to a post-Enlightenment culture that has come to depend on naming and categorising as fundamental for understanding. However, if we fail to recognise that worship transcends and mystifies human knowledge, that it is not something to be grasped, but rather an experience in which we are grasped by God,[48] we are in danger of falling into a type of reductionism that is a counterpart to the medical reductionism we previously saw as being so destructive to people with learning disabilities.

[46] Matthew 18:3.
[47] B. Easter, 'Worship with people who have mental handicap: personal and pastoral implications', in S. Pattison (ed.), *Mental Handicap, Theology and Pastoral Care*. Pastoral studies spring conference proceedings, University of Birmingham, Department of Theology 1986, pp. 44ff.
[48] S. Kierkegaard, *Søren Kierkegaard's Journals and Papers*, trans. H. V. Hong and E. H. Hong, Princeton University Press 1967–78 (7 vols), 4/3956, X3 A777 (1851).

In worship Stephen encounters his friend 'Jeeshuss' in the presence of the friends of 'Jeeshuss'. The core of his life with others is not status or achievement, but the simple, the unspoken question: 'Are you my friend?'[49] In this encounter he discovers happiness, value and acceptance and sings and reacts in response. Of course, we may ask, does Stephen recognise the divine referent of such experiential worship? Maybe not, although who can tell? Nevertheless, as Pailin correctly suggests, unless our conception of God is that of an egotistical despot, who demands recognition before accepting relationship, we would have to answer 'does it matter?'[50] Surely the object of God's salvation is loving transformation, manifested in the restoration of broken relationships, and not some idolatrous lust for power on His behalf. If we view God as self-seeking and demanding of recognition, we are in danger of projecting onto Him our own self-centredness, and insecurity. Surely 'love loves. It does not seek payment.'[51] Concrete experience of friendship-in-worship symbolically reveals the 'inexpressibleness' of the transcendent God of love.[52]

If we take seriously Stephen's contribution to our understanding of the worshipping community we find that the perspective he brings opens up a whole new dimension on what worship is and what it means to be a worshipping community. In the music, in the dance, in the bread and in the wine he encounters a joy and evokes a sense of celebration that surpasses rational understanding and deeply challenges a church that equates faith and knowledge of God solely with intellectual comprehension.

The significance of words

It remains true of course that words and intellect are important for the life and worship of the church. However, we must never lose sight of the fact that words only *point* to the reality they refer to. They are not the reality itself. It is the actuality that matters, and not our self-conscious identification of it. *Words provide a way of enabling people to become aware that what they experience, in some of their encounters with other people, is an experience of the character of their relationship with God.*[53] As Christians, the divinely ordained purpose of our words is that

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[49] Many [people with learning disabilities] intuitively grasp the ingredients of friendship such as reliability, trust, intimacy, and a bond of true affection. The core of their life together and with others is not status or achievement, but 'Are you my friend?' B. J. Easter, 'A theology for people with mental handicap', *All People* 34, March 1986, p. 14.

[50] D. Pailin, *A Gentle Touch*, p. 137.

[51] D. Pailin, *A Gentle Touch*, p. 137.

[52] D. Pailin, *A Gentle Touch*, p. 137.

[53] D. Pailin, *A Gentle Touch*, p. 133.

people should live fully,[54] and that our lives should be transformed experientially as we encounter human and divine loving relationships. Words certainly help us give an accurate response to God and to one another, but they take on their true meaning only as they are worked out within some form of community. As Stephen Pattison astutely observes, 'Only in action can the meaning of love and compassion be revealed.'[55] The task of the worshipping community is not simply to proclaim the word, but to incarnate it within its structures of worship in order that the meaning that is being communicated is clear and meaningful to *all* who seek to worship and befriend 'Jeeshuss'.

The significance of the Eucharist

Stephen loves to participate in the Eucharist. In sharing the bread and the wine, he experiences something of the love and acceptance of Christ mediated through the concreteness of the elements. It is true that he does not comprehend the theological significance of the elements, at least if we define comprehension in terms of the ability to grasp abstract theological concepts. However, his experience of performing the Eucharist is filled with meaning by those around him, who provide a context within which he feels secure, loved and a part of a worshipping community. For Stephen the Eucharist is a communal meal that he participates in with his friends. Certainly it may not have the same meaning that 'theological correctness' demands. But then again, who amongst us truly understands the mystery of the broken body and the blood of Christ? I would suspect that if we went round the average church congregation and asked the participants to define the meaning of the Eucharist there would be multiple answers, and many would not have a clue what its 'true' theological meaning is. There is no good reason why we should deem it appropriate to ask questions of people with learning disabilities that we would not ask of the majority of people who actively participate in our services of worship. Participating in the Eucharist enables Stephen to feel something of the fellowship of Christ in the form of an experience that is tangible, wordless, but no less meaningful, its content fleshed out by the accompanying experience of the friendships of the worshipping community. Christ comes to Stephen in the mystery of the Eucharist in a way that cannot be understood with the mind, but which *can* be experienced, grasped and lived out within his life. As Brian Easter puts it:

> We will not ever fully comprehend the heart of the Sacrament, we can only apprehend, and grasp it with faith. The narrowly intellectual cannot in principle be the criteria for experiencing or

[54] John 10:10 'I have come that they may have life, and have it to the full.'
[55] S. Pattison, *Pastoral Care and Liberation Theology*. Cambridge University Press 1994, p. 32.

admission to the Sacrament, but the experience of being accepted, wanted and loved as a recipient of grace.[56]

Challenging the church to be the church

To think about worship in these ways is challenging and for some it will be quite disturbing. To suggest that we should learn the meaning of worship and how to perform it from someone who has no knowledge of theology and no experience of formal liturgy is, to say the least, an unusual proposition. Some might even say it was foolishness. But accusations of foolishness are a not uncommon response to the preaching of the Gospel. As St Paul says: 'the foolishness of God is wiser than man's wisdom, and the weakness of God is stronger than man's strength.'[57] The task of the Body of Christ is not to do what is sensible and reasonable. Nor is its task to please or appease the majority. The task of the Body of Christ is to remain faithful to the one who sat with tax collectors and sinners, who embraced the 'unloved', and who ultimately laid down his life for his friends. It is the person of Christ and not our cultural assumptions and norms which shapes and sets the parameters for our worship, as he does for the whole of our lives. If we are truly one in Christ, this oneness must be fully reflected in our life and worship together.

Responding to the transforming presence of Stephen in our worship will be a costly business for the Christian community, and some will find themselves unable to walk the road. We will need to reconsider some of our standard patterns and structures of worship that may well act to exclude him from the vital heart of the worshipping community. Whilst retaining the importance and significance of words, we will have to look beyond them and begin to rediscover the simplicity of love, the power of experience, the beauty of dependence and the gift of vulnerability. In the light of the theological perspective developed previously, it is important that we understand fully what is being said here. Such changes of practice in response to Stephen's situation must not be seen as acts of charity. Changes in the practice of worship are not done simply to 'accommodate people with learning disabilities'. Such an approach begins with the assumption that Stephen is a stranger rather than a friend. We cannot truly be transformed if we assume that we are doing this for 'them'. We can only understand the need for change when we realise that we are making it in order that the Body of Christ can be made whole. The changes we make within the practice of the church are made on

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[56] B. Easter, 'Sacraments and MH people' *Liturgy* 9 (5), June–July 1985, 196.
[57] I Corinthians 1:25.

a mutual basis for the assistance of all, that all might participate more fully and easily, that all might be able to offer their gifts and that all might be able to benefit from all the gifts offered.[58]

Such changes in perspective and action are acts of faithfulness and love, as the church strives more accurately to reflect the image of God within the Body of Christ. Only when she can begin to see things from this perspective will it be possible for the church to introduce the changes that will ensure Stephen and all who share his position a meaningful place within its communities.

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[58] J. Peirce, 'Learning from disability', *British Journal of Theological Education.* 8(1), Summer 1996, 46.

4. Conclusion

As I read and reflect on the snapshots of Stephen's life I have presented within this monograph, it is clear to me that what I have offered is in fact two narratives that are inextricably intertwined: Stephen's story and my own story of the impact that being with him has had on me and the way that I see and have come to understand the world. In a sense this is strangely appropriate. If we take seriously the apostle Paul's language concerning the Body of Christ as I have interpreted it here, it becomes clear that people with learning disabilities are not a group that stands somehow apart from the rest of the Body and whose special needs have to be catered for apart from the needs of the whole Body. Rather they are integral to the very shape of the Body. Our task is not to attempt to shape them into heads, arms, legs or any other body part. The task of the Body of Christ is to accept them precisely as they are, and to allow their stories to become part of its own continuing story. The transformed understanding that arises out of such a sharing of narratives will change the ways in which we understand the Body of Christ, and indeed how we understand God. Stephen's story is our story. The Christian community must listen to him if it is to understand not only who he is, but also who and what *it* is.

As we reflect on where we have been during this essay, it is clear that listening to Stephen's story and exploring the realities of his life-world is a dangerous enterprise. Implicitly and explicitly, Stephen challenges our understanding in ways that cause us dis-ease and force us to reflect upon areas of life, church and ourselves which we might wish to remain hidden. Stephen's life and experience offer the church both a challenge and a promise: the challenge is to our theology, our values, our attitudes, our church structures, and our ideas about what it means to be a human being called to live out the image of God. However, in accepting that challenge we discover a promise: the promise that by allowing Stephen's experience to lead us into new ways of understanding and love, humility, dependence and vulnerability, we can discover a fuller and deeper understanding and outworking of the Gospel. Unfortunately, for many of us the challenge drifts by unnoticed, and the promise is never fulfilled. The attitudes, lack of understanding and compassion, ignorance and enforced physical and psychological segregation experienced by people with impairments such as Stephen's inevitably throw up major questions as to whether or not the church is being faithful to Jesus' boundary breaking mission, a mission that sought to incorporate marginalised

people within God's emerging Kingdom of love. The Christian community, with its multiplicity of gifts, abilities and talents, is well equipped for the task of enabling genuine integration, and has much to offer to people with learning disabilities and their families.

Of equal importance is the fact that the community has much to learn and to receive from people who experience the world in the way that Stephen does. Friendship in the context of authentic, Christian community is a vital element in the fulfilment of the task of being the church. Mutuality and interdependence, with each member accepting full responsibility for the welfare of others, is the ideal that we must strive for. If Stephen is to play a creative role in such a community, then it is vital that we acknowledge that the responsibility for engendering an atmosphere of acceptance and belonging that will enable his full participation must be taken seriously by the entire community, and not simply left to the few who are considered 'experts' or to be 'gifted in this field'. Shifting responsibility to the 'experts' all too easily allows the abrogation of an inherent responsibility within the Body of Christ which each member has towards the others.

As human beings, we are made in the image of God. In each of us that image is damaged and tarnished, as our relationship with God is broken, leading to the consequent loss of community and harmony. However, the image of God begins to be restored in the Body of Christ, when each individual is affirmed for what he or she has to contribute to the total image. The image of God can begin to be restored only within a community that allows the many and varied aspects of God's people to be manifested in different ways. If we accept that Christ alone is the true image of God,[59] both relationally and ethically, then it is against His standard that all values stand or fail. In Him we are a new creation, and together we form the Body of Christ. Within such a structure, the exclusion and degradation of people with profound disabilities at any level are inevitably excluded. Within the community of Christ, Stephen can be seen to belong as himself, valuable and worthy *because* and not in spite of his differences. The segregation and prejudice which are often imposed and sometimes even glorified by the world should be actively anathematised both in Word and in prophetic action, in order that the true values of the Kingdom can reign in our churches.

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[59] 2 Corinthians 4:4.

5. Postscript

Since I began to write this monograph, Stephen has turned eighteen and has moved into sheltered accommodation. It is difficult to know what his future is and how his relationship with the wider church community will develop. A good deal depends on whether the churches in his area take seriously the issues that have been discussed within this monograph and take the initiative to reach out and draw him in. I am not optimistic. I suspect that most of them will not even have begun to wrestle with the complexities of Stephen's life that we have explored here. If this is so, the task of making whole the fragments of the vision that I have offered belongs to the readers of this monograph. I long for the day when caring for people like Stephen becomes the passion and purpose of the people of God in every place where Christ would be today. Whilst Stephen may not live next door to you (although he may), there are many other Stephens who are seeking the Kingdom. Your task – our task – is to make real the promises of the Gospel, as we embody the life of Christ and live it out in committed, passionate friendships with those whom the world rejects. That is our vision, our task and the source of our joy.

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